

HIV/AIDS

WORK GROUP ON HEALTH CARE ACCESS ISSUES for African Americans

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U.S. Department of Health and Human Services
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Bureau of Health Resources Development

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for African Americans

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U.S. Department of Health and Human Services
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Introduction

The Health Resources and Services Administration, Bureau of Health Resources Development (BHRD), sponsored a Work Group on Barriers to HIV Care for African Americans on February 22 and 23, 1993. Nineteen African American participants, as well as six Federal representatives, met to discuss issues related to barriers to the provision of HIV/AIDS services to African Americans. The participants, from diverse backgrounds, experiences, and regions, were selected because of their knowledge of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, their participation in its implementation, and their involvement in identifying communities' HIV care needs. Several participants were people living with HIV disease. However, this group could only partially represent the regional, cultural, and socioeconomic diversity of this nation. The work group members shared a commitment to improving access to HIV care for African Americans.

Objectives

This work group is one of a series of such meetings convened over a 3-year period by the Office of Science and Epidemiology (OSE) and the Division of HIV Services (DHS) within the Bureau. The primary objective of each meeting is to understand—from the point of view of underserved populations and those who serve them—the barriers to providing HIV clinical and support services. The insights about the availability, accessibility, and acceptability of specific medical and support services will assist the Bureau in evaluating the CARE Act and providing technical assistance to grantees to more effectively deliver services to people with HIV.

The work group on barriers to care for African Americans grew out of a concern about the disproportionate impact of HIV in African American communities and a desire to identify the problems of delivering services to affected communities, including historically underserved communities. Specifically, the work group members were asked to help the Bureau:

- understand issues related to African Americans' access to HIV/ AIDS care funded under the CARE Act;
- propose and draft evaluation study designs; and
- identify areas for technical assistance.

In addition, the work group was asked to identify health service researchers working on topics related to HIV/AIDS, members of affected populations, and individuals who deliver health care and support services to serve as consultants. The group also was convened to develop methods and strategies to systematically assess whether and how the CARE Act is working to bring emergency relief to African Americans affected and infected by HIV disease.

Background

The Ryan White CARE Act

In 1990, as a response to the critical need for basic medical and support services for people living with HIV disease, Congress passed the Ryan White Comprehensive Resources Emergency (CARE) Act. The CARE Act became law on August 18, 1990 and first received appropriations in November 1990. The principal objective of the legislation is "...to provide grants to improve the quality and availability of care for individuals and families with HIV disease..."

Titles I and II of the CARE Act are administered by the Bureau of Health Resources Development (BHRD), part of the Health Resources and Services Administration (HRSA). Grant funds, under Titles I and II, are awarded to the Eligible Metropolitan Areas (EMAs) most heavily affected by the HIV epidemic (Title I) and to all States and U.S. Territories (Title II). The grants are used primarily to fund ambulatory, outpatient, and community-based care, including both medical and social support services, for individuals and families with HIV and AIDS who are not insured or lack critical services.

The CARE Act is founded on two basic tenets: (1) that people and communities affected by the HIV epidemic be included in planning and setting priorities, and managing the provision of care, and (2) that the comprehensive care needs of individuals with HIV and AIDS be met through a continuum of planned and coordinated services. Despite these tenets and the requirements of the CARE Act, BHRD recognizes that there are barriers that limit or prevent underserved populations from obtaining access to care. Many barriers to care existed before the HIV epidemic, but the crisis of the epidemic has drawn attention to the need to remove them.

The HIV Epidemic within African American Community

The HIV epidemic disproportionately affects African American populations.¹ CDC statistics provide a sobering profile of the HIV epidemic for African Americans. While Blacks comprise approximately 12 percent of the U.S. population, more than 32 percent (130,384) of the cumulative AIDS cases are American Blacks. Fully half (54 percent) of the women

who have been diagnosed with AIDS are African American and almost 29 percent of men with AIDS. Among African American males, more than 48 percent of AIDS cumulative cases were exposed to HIV through sex with other men. More than half of the women with AIDS contracted HIV through injection drug use, and an additional 18 percent were exposed to HIV through the drug use of their sexual partners. African American children accounted for 55 percent of all reported pediatric cases in all races last year. Recently, CDC reported that HIV is one of the five leading causes of death for African Americans and the leading cause of death for Black males age 35-44 years². Certain cities have been hard hit. Blacks represented 75.5 percent of the cumulative AIDS cases in Baltimore, while comprising only 59.2 percent of the population; and in New York City, Blacks claimed 39.6 percent of the cases, but represented only 28.7 percent of the city's population.

The summary that follows reflects the frank and diverse opinions of the participants. While the participants did not always agree on recommendations, contradictory recommendations provide the basis for developing studies to clarify the limits of various service delivery modes. The participants commitment to stopping the spread of HIV in their communities and improving services for people living with HIV was evident. Also evident was the frustration that some felt from working on HIV and other problems within their communities. Although the breadth of participant recommendations sometimes exceeded the Federal authority, they provided valuable insights into the issues surrounding the implementation of Federal programs. The following is a summary of their frank discussion and thoughtful deliberations.

¹Centers for Disease Control and Prevention HIV/AIDS Surveillance Report, June 1994, Vol. 6, No. 1.

²MMWR, November 26, 1993, 42(46): 891-900

Summary of Proceedings

On February 22, following brief introductions and a review of meeting objectives, participants began to discuss barriers experienced by African Americans with HIV who have sought HIV care and support services. As part of the discussion, members of the group stressed the importance of placing this meeting in a historical and political context. The context they framed included the legacy of slavery, discrimination, and public policies that promote dependency. Participants agreed upon a working definition of the term “African American” or “Black.” It was agreed that for the purpose of the meeting, these terms would refer to all persons of African descent residing in the United States.

After introductory remarks, barriers to care were discussed and issues identified for further development in break-out groups. Presentations on African American perceptions of health in two cities (Baltimore, Maryland and Oakland, California) set the stage for the small group discussion linking barriers to care issues to proposed technical assistance and evaluation studies.

The group identified seven areas for proposed technical assistance and evaluation studies as follows:

1. The characteristics of information systems that work for African American communities;
2. Minimum standards of services to increase effective access, utilization and evaluation;
3. Identifying and institutionalizing community-based training and technical assistance models;
4. Identifying resources of and for African Americans and developing a directory of services and skills and a dissemination plan;
5. Characteristics of organizations that move from “good works” to “good work”;
6. Assessing whether African Americans and their needs are addressed in decision-making arenas and the planning council processes; and
7. Comparing African American community-based organizations (CBOs) with non-minority AIDS services organizations (ASOs) that have African American service components.

Participants divided into three smaller break-out groups, charged with drafting study designs, identifying technical assistance needs, and formulating specific recommendations. On February 23, the break-out groups met in the morning and early afternoon, and presented their findings at a plenary session during the afternoon closing session. Public and private agencies were invited to hear and react to the preliminary report.

The following summarizes the two days, including the general discussion, the presentations on Baltimore and Oakland, and the recommendations of the three break-out groups.

Proceedings

General Discussion About Barriers to Access

The introductory remarks of Moses Pounds, Office of Science and Epidemiology, and Gary Cook, Division of HIV Services, generated considerable participant response and discussion. The participants stressed the importance of beginning the meeting with descriptions of their experiences in seeking care and working with the implementation of the CARE Act at the Federal, State, and local levels. Many participants stated that the CARE Act was not meeting its objectives from the standpoint of African Americans. Several people suggested that there may be fundamental flaws or limits within the legislation as written; others suggested that program management might effectively address some of the issues.

As borne out by the discussions of the work group as well as by the suggested areas of evaluation and technical assistance, there is serious concern in the African American community that resources and services are not reaching African American individuals affected or infected by HIV. Further, African American organizations that might otherwise provide these services in a more effective and culturally appropriate manner too often are not used, lack the capacity to deliver HIV/AIDS services, or have not made a commitment to responding to AIDS in their communities.

Participants discussed their concerns for better representation of African Americans in the planning council process; accountability of those in decision-making roles; the need to understand—through evaluation—which health service delivery strategies are most effective for attracting and keeping African Americans and their communities in treatment; and the need to monitor and improve the local funding process—through technical assistance—to provide for better access to funds by African American organizations.

Historical Contexts

Several participants stressed the importance of placing the work group's discussion within the historical and political context of African Americans. The context for AIDS in the African American community is influenced by a history of discrimination against African Americans, high

rates of substance abuse, mistrust of institutional systems, homophobia, and conspiracy theories of genocide. Often, those who are responsible for the design and implementation of HIV programs have no direct knowledge of the intended recipients, and thus lack credibility with them. Finally, because many African Americans have poor health status and limited access to care, the HIV epidemic has been particularly devastating. Other major health concerns compete with HIV for attention and resources within the Black community, i.e., violence, substance abuse, heart disease, cancers, and teen pregnancies.

Prejudice and bigotry—whether intolerance or institutionalized racism—continue to be part of the Black experience in America. The staff and policies of social service and health programs are frequently insensitive to the cultural experience of African Americans. The group indicated that tragedies, such as the Tuskegee syphilis study, are reminders that public health officials have betrayed the trust that Blacks have placed in them. Work group members reported that in Black communities, HIV is associated with experimentation and exploitation and contributes to delays in seeking treatment. In the African American community, there are strong rumors that the HIV virus is man-made as an agent of genocide directed against Blacks. There are similar conspiracy theories regarding the introduction of illegal drugs into the Black community. These theories contribute to a distrust of government efforts to prevent and treat HIV.

Some members of the group voiced the opinion that the stated motives for scientific research and public health are not trusted by disenfranchised Black people. There are perceptions that campaigns to improve the health status of African Americans have not significantly reduced diseases such as cancers, heart disease, and diabetes. Thus, unless they develop credibility over time, AIDS outreach workers face skepticism that HIV prevention and treatment programs will benefit African Americans who are poor and disenfranchised.

Public health programs are seen as alienated from many African American communities. Too often, these programs are perceived as reflecting the priorities and needs of researchers and institutions that are not accountable to poor African Americans. Participants offered examples of HIV prevention and education messages that were poorly conceived communication programs with irrelevant media, symbols, and messengers. HIV educational information must be created and delivered by credible African American spokespersons in order to encourage people with HIV disease to seek treatment.

Several members of the group strongly stated that the CARE Act program, as currently structured, often selects service providers without experience within Black communities. There was intense discussion about how much the CARE Act could do to address long-standing problems of the poor, such as housing, employment, drugs, and racism. While the group acknowledged that CARE Act programs could not solve these broader problems, they expressed the need for a greater commitment to establishing accountability and building the capacity, within Black community-based organizations, to serve African Americans.

HRSA's Response: Drs. Bowen and Goosby responded to the concerns and issues raised by describing how the agency has responded to reduce barriers to care for all disenfranchised populations throughout the country, including African Americans. They pointed out that within HRSA there are numerous people who are African Americans. These highly skilled and competent individuals occupy positions of authority in HRSA, including five project officers for CARE Act grants.

Generally, the intention of the CARE Act is to improve community involvement in the organizing, planning, delivery, monitoring, and evaluation of HIV care. The CARE Act is implemented within local social and political environments over which HRSA has no authority. However, working with grantees as legislatively mandated, the agency and its staff strive to implement in each city and State the stated goals of inclusiveness, representativeness and delivery of care to all communities. Of particular concern to HRSA staff are problems and issues related to African Americans, such as access to acceptable and respectful health care and participation in decision-making. Drawing on the insights of this and previous work groups, the agency will strive to improve the program from the perspective of people living with HIV and the providers serving them. The evaluation studies and the technical assistance recommendations from this work group will serve to inform agency's project management, resulting in improved programs at the provider and grantee level.

Using evaluation as a mechanism, HRSA will promote well-designed studies using appropriate methods to evaluate projects that strive to bring African Americans into care and keep them in there. Participants from this and other work groups have observed that grantees and providers often can reduce barriers to care and improve the experiences of those seeking treatment by creating an atmosphere that is receptive to and

respectful of people with HIV disease. An essential part of evaluation, planning, and delivery of services is to involve people with HIV at all stages of the process, including client satisfaction surveys and other client input to improve needs assessment and service priorities in each community.

Perception of Services Before the CARE Act in Two Cities

As an example of the studies that might be undertaken by the Bureau and to set the stage for the deliberations on evaluation studies and technical assistance, studies of HIV service delivery before and after the receipt of CARE Act funds were presented. The studies were conducted in two cities by Amanda Houston-Hamilton, D.M.H., in Oakland, California, and Tony Whitehead, Ph.D., in Baltimore. The purpose of the studies was to assess local residents' perceptions of the availability of HIV-related services prior to the implementation of the CARE Act funding in each city. Each researcher sought individuals with HIV who were not necessarily in care for in-depth interviews. A theme that runs through the findings of both studies was that the informal support systems were neither recognized nor used by the health care agencies having formal responsibility for bringing Blacks with HIV into care. Each study involved a variety of methods: focus groups, group interviews, and individual interviews.

Recommendations from the Baltimore Project:

1. Sensitivity training for health care professionals;
2. People with AIDS (PWAs) providing 20-25 percent of training;
3. Collecting opinions of PWAs before/during/after services are planned/delivered;
4. Establishing independent review boards that avoid conflict of interest on planning councils;
5. Mandating that programs be responsive to consumers and not the institution;
6. Initiating more support groups that are responsive to various segments of the community;
7. Creating more employment opportunities for PWAs;
8. Providing more affordable housing for PWAs;
9. Using PWAs as consultants ; and
10. Conducting research that holistically evaluates the needs of people with HIV disease.

Recommendations from the Oakland Project:

1. Consider HIV delivery issues simultaneously with a wide range of social, organizational, and logistical issues (i.e., coexisting conditions/diseases, family systems, residential arrangements, transportation needs).
2. Do not ignore or dismiss the diversity within each community. Diversity must be seen in the sexual orientation, gender roles, ethnic cultures, etc.
3. Pay attention to the differences between social networks and social support. Sometimes social networks are not supportive. Providers need to be innovative in turning social networks into supportive ones with practical solutions ("I don't want people in my business").
4. Develop the awareness and skills of service providers to identify and use beneficial social network, including "families" and friends.
5. Encourage and train providers to listen to how people want to be helped. Their preferences are often not the same as service providers.
6. Use women to talk to women (as mothers, aunts, sisters, etc.)
7. Identify and use respected people living with HIV as experts; they often have more credibility with people who are comparing and exchanging opinions on services.
8. Providers should expect that clients will test them to see if they can be trusted.
9. Intensify efforts to educate patients about the full range of HIV services within an agency as well as within the larger community.
10. Providers should examine their organizations for oppressive conditions. These are often degrading experiences ("... 'the price of the ticket' for getting treatment is 'often going along with the system' ...").
11. Technical assistance plans should be developed and carried out in collaboration with the intended recipients.
12. It is important to understand the limits and parameters of mandated "one-stop shopping"; it limits the choice and options for the consumer who wants to use a variety of providers for his/her medical and support services needs.
13. Aggressive efforts are needed to stop the practice of keeping African American agencies and community-based organizations off the referral lists. People do it because they like working with people they know.
14. Providers must identify the barriers to use of services from the users point of view. "Some people talk about the number of buses they have to take to access services, versus others who talk about how close services may be to a bus stop."

Barriers to Care in African American Communities

Drawing on their own and their clients' experiences, the participants described examples of cross-cultural conflicts between service provider staff who were not African American and local African American clients. The discussion suggested that these conflicts can be motivated by bigotry or caused by ignorance without malice. In either case, people seeking care develop negative impressions of the agency and its staff, which can lead to decisions to seek care elsewhere or to delay seeking care until the illness becomes debilitating.

The participants offered examples of successful strategies to overcome cross-cultural conflicts. These included locally designed and implemented projects that are responsive to community needs. The comments could be summarized into five thematic areas:

1. HRSA and the CARE Act programs lack credibility among African Americans.
2. African Americans share some of the responsibility for shortcomings in the health care system. There is a lack of African American leadership, accountability and credibility at various levels within Federal, State and local government (HRSA, planning councils, and community-based organizations), which contributes to the existence of barriers to care.
3. The HRSA work groups on access to HIV care are important and welcomed.
4. The lack of resources available to reach African American communities acts as a barrier to access.
5. There are a number of alternative strategies for reducing barriers to care.

HRSA and CARE Act programs' lack of credibility among African Americans.

Several participants vocalized strong doubts about the credibility of the work group process and HRSA's ability to overcome societal and systemic tendencies to discount African Americans in general and, more specifically, African Americans with HIV, or with HIV and addictions. They

asked for assurances that their participation would lead to changes in the program that, in turn, would lead to an increase in African Americans' access to HIV care. There was general concern that this would be another disempowering experience. As a result of this perceived lack of respect for African Americans, especially for those with HIV or with HIV and addictions, African Americans lack confidence in HRSA and the CARE Act programs.

The issues that emerged included exclusion of African Americans in the policy and decision-making process during implementation of the CARE Act programs in their communities. There was agreement that knowledgeable and involved HIV-affected and infected African Americans must be accorded credibility and status in policy formulation, service delivery, planning and implementation. This includes participation in evaluation studies, membership on planning councils, and participation in deliberations when HRSA interacts with affected communities. Some participants were concerned that this work group process not mirror past experiences of the Black community with public agency initiatives. Specifically, they wanted assurance that concrete actions would result from their recommendations, and not just another report. They also were concerned that future evaluation studies emphasize quantitative over qualitative data. Qualitative studies capture the distinctive nature of community-based programs, while quantitative studies often reduce people to numbers. The members of the group strongly recommended that the work group process produce study designs that are practical, relevant, and clearly beneficial to communities of color.

The doubts and concerns over whether HRSA would or could really listen and respond to the concerns of African Americans, including persons with HIV and addictions, were expressed by statements such as:

"...(there are) two-hundred years of experience in this room...what about credibility?... people, without degrees, the very people who we are trying to help, do not get recognition (by HRSA or society); they need to be heard...Black folks are not heard...I hope our intent is to be heard through this process..."

"...The State ignored the Detroit Health Department because it was Black...White organizations are in touch with HRSA (about funding issues) before the Health Department gets to hear about (funding issues)..."

"...Ryan White is rigged, the deck is stacked...Blacks are not getting funded..."

Participants discussed two ways in which this bias operated: (1) the fact that little has been done to deal with African Americans' lack of trust of the scientific research community; and (2) the lack of appreciation for the need for translators between lay persons in the African American community and those who speak the language of bureaucracy and research. Lay individuals who often do not understand bureaucratic or research idioms may be excluded from the evaluation process. As a result, their exclusion may mean a loss of valuable information and insights into the problem being evaluated. Specifically, participants stated the importance of including injection-drug users, for example, in evaluation studies on access to care.

"...Research and CBOs don't easily mix, because of trust issues...research should allow the community to understand the information—combine the numbers and the faces...research should be a partnership asking what questions do you (the community) want asked...also sharing in the glory of publishing...folks should not be used, then hurt..."

"...addicts can be mobilized, but we do not have the idiom [professional terminology] to be taken seriously. People at all levels need to be involved... we need to find idiom exchange agents...addicts can give credibility; their power is the fear that they can disrupt..."

The lack of effective leadership and accountability from African Americans: a limiting factor.

Participants expressed concern about the lack of effective leadership and accountability from African Americans participating in organizational structures and processes of the CARE Act programs. Historically, African American leadership in HIV issues within public agencies and as community leaders has been lacking. Participants expressed concern that many African Americans had abdicated their leadership in HIV. Without effective leadership, attitudes about drug addiction and homophobia will undercut efforts to deliver services effectively to people with HIV disease. Several participants, however, gave examples of effective African American involvement and leadership that they encouraged. Sometimes this takes the form of alternative means—outside of the CARE Act program implementation process.

"...We have not held African American bureaucrats accountable or supported them..."

"...When HRSA project officers come out we are the only ones in the African American community who are consulted. Really speaking out endangers what few resources we already have..."

"...HRSA should take the money (back) if you are not serving Blacks, even though you have Blacks on your board...Blacks in (board) positions are not delivering...it seems we are afraid to go to court...we have people with melanin at the table that are not (really) Black..."

"...In Virginia, the request for proposal (RFP) process resulted in no minority organizations getting funded. A woman (African American) said no and got a (court) injunction and the process was reviewed for fairness..."

"...In Philadelphia the Minority Consortium took over Ryan White..."

"...None of them (national civil rights organizations) was going to touch homosexuality and addiction... what has changed is the money..."

"...HIV is often a low priority among African American leaders. How do we make leadership accountable?..."

"...Major barriers to our care relate to the law (CARE Act legislation), not attitudes in the Black community...we should look at the system issues...there are system issues, there are policy issues, there are cultural issues..."

"...People deal with HIV as a moral issue, not a public health issue, and we do not advertise the fact that we have this problem. More people would get involved if we did..."

"...There is a game going on, and some players are people of color, and persons are not being served. The issue is accountability of agencies and systems. There has to be a way of supporting the informal systems that people use..."

Importance of the HRSA work group process.

Although several participants expressed strong reservations about HRSA's credibility and accountability, and the limited effectiveness of some African Americans involved in the CARE Act implementation, they generally agreed, with cautious optimism, that the work group process was a welcomed opportunity. Members of the group were eager to make recommendations and to work with HRSA on studies that may point to solutions for increasing African Americans' access to CARE Act services.

They were hopeful that these studies, with input from community-based people like themselves, would lead to improved access to HIV care for African Americans.

In particular, the group discussed the value of qualitative methods in capturing and analyzing approaches that have been effective in reaching their communities. While quantitative methods are important, they do not describe, categorize, and analyze how minority-run programs are effective. In contrast to counting services or clients, qualitative methods are designed to consider the point of view of the recipients of the services and their interactions with the agency. This leads to a richer description of community-based programs and is likely to capture the reasons they succeed. The group expected that qualitative methods, in combination with other methods, would increase attention to and appreciation of local efforts. That, in turn, would increase the likelihood that more Black community-based organizations would be funded to deliver services to Blacks. Further, they stated that study methods would help the development, adaptation, and dissemination of the wide range of strategies that are being used in African American communities.

"...The numbers won't mean anything, so we need qualitative information; we are getting standardized quantitative information..but numbers won't mean anything without understanding the context..."

"...On-site visits by HRSA, you get the dog and pony show, and this has its limitations in terms of understanding what's really going on..."

"...Groups like this (HRSA work groups) are important...we need them to get more accountability from grantees, to find out who actually is being served, and about quality of service by providers outside and within black communities..."

"...We need to get together and learn what happened. How do grassroots organizations get empowered?" How do Black organizations survive?..."

"...It's an opportunity to say how Ryan White funds affect your community and to propose technical assistance..."

Lack of resources in African American communities.

"...Many minority people do not have medical insurance. How are we going to get the services that our people need? Other groups have more resources. The strongest group is the gay white community. If you can go to every gay white meeting, maybe you can access more resources..."

"...If you are a white man in Seattle with HIV you can get services; the homeless need services..."

"...(Federal) AIDS money is not supplementing State funding, it is supplanting State funding..."

Strategies and suggestions offered for improving access through the CARE Act ranged from local initiatives for effectively reaching Black people with HIV to policy recommendations for grants management and reauthorization. Generally, there is a pressing need for planning councils to coordinate actions within their processes and link HIV issues with action in other arenas, such as the legal, political and housing arenas. A continuous evaluation program at the local level will ensure that studies are conducted to identify effective ways to improve access for Blacks.

During the discussion, one participant raised a concern about "one-stop shopping" models of service delivery. He suggested that an unintended, and from his perspective undesirable, consequence of restricting people to only one source for all their care needs is that choice may be reduced, and a mistaken impression that Blacks do not want the full range of choice of providers may result. However, in many cities and rural areas, provider choice for African Americans with HIV disease means seeking care outside the Black community. The group agreed that the intent of developing resources within Black communities was to expand the number and type of agencies available to African Americans seeking care.

Strategies to Reduce Barriers

The following suggestions were based on the personal experiences of the participants or their knowledge of issues that had affected the implementation of CARE Act services in African American communities. Some of the ideas mentioned included:

1. Become politically active and organize allies to support your representatives on local planning councils or consortia (get involved and become an effective force representing our community);
2. Ensuring that African American addicts and recovering addicts, women, and people with HIV are involved in every stage of the planning and funding process;
3. Petition courts to obtain injunctions when funding decisions are made that exclude African American organizations ("I threatened legal action in order to get a seat at the table.");
4. Choose meetings and level of participation carefully ("Some meetings, where funding decisions are made, are essential to attend that's where things get done.");
5. Make HRSA aware that African Americans are not served, even though African Americans are involved in the decision-making process;
6. Distributing funds in proportion to the population in need of HIV services;
7. More networking among African Americans to share strategies that are effective within their communities;
8. Collaborating with other groups and individuals ("Those of us who are very involved are very few. We need to come together and assign tasks.");
9. Educating ("Consumers can keep their providers accountable. We can educate consumers about the services they should be getting." "A city should spend resources on how to access the system." "Most (consumers) do not understand how the system works.");
10. Understanding effective African American organizational and organizing models ("Grassroots organizing has not changed since 1960." "There are local organizations that have been serving folks for years. We are not about to let newcomer national organizations with little experience with HIV set the agenda for the Black community.");

11. Strategies of organizing for empowerment “needs to be explored”;
12. Fighting homophobia, addictophobia and classism in the African American community;
13. Educating the community about HIV as a public health issue versus a moral issue;
14. Using comprehensive/holistic approaches to delivering services resonates with African American cultures (“it is not African American to fragment things.” “We have to approach things comprehensively, not as the dominant system does—compartmentalizing everything. I am not pitting my daughter against my son, or against my aunt or against my gay cousin—we are one.”);
15. Examining health and social systems issues;
16. Examining policy issues; and
17. Examining cultural issues.

Break-out Group Recommendations:

Proposals for Evaluation Studies and Technical Assistance

I. Break-out Group #1

Participants: Tony Whitehead, Joan Fields, Floyd Dunn, Robert Scott, and Amanda Houston-Hamilton

Break-out group #1 was assigned the task of looking at five overarching areas for evaluation studies. These were: (1) information systems that work with African American communities; (2) availability of the continuum of services that increases chances for effective access and utilization; (3) identifying and institutionalizing community-based training and technical assistance models; (4) identifying resources of and for African Americans and developing a directory of services and skills; and (5) the development of organizations that move from “good works to good work”—from well-intentioned efforts to ones that actually benefit recipients. As part of their recommendations, the group also made suggestions for technical assistance in each of the five issue areas.

1. Information systems that work with Black communities.

Break-out group participants identified seven sources and systems for information exchange in the African American community. The diagram on page A-2 in the Appendices illustrates how these sources and systems are part of an integrated whole and how they relate to the individual. Successful African American CBO programs have many of the following characteristics. Further, programs based outside of African American communities should consider these features when designing projects. Participants in the group cautioned, however, that simply imitating African American projects will not necessarily be successful. The project needs to be “of the community” and not just “in the community.” The identified sources and systems of information with those characteristics were:

- Elders involved
- “Family” - Afrocentric definition
- Spiritual Community - not just religion
- Social networks that are locally defined
- Peer-to-peer self help
- Drum (community consensus building)

- Agencies not usually considered by funding sources:

- Churches and religious communities
- Educational institutions
- Beauty and barber shops
- Supermarkets
- Forums
- Public hearings
- Block clubs

1a. Key evaluation research questions

- The need to understand how best to promote cooperation and coalitions to take advantage of information systems that work and to help promote existing African American agencies in becoming involved in HIV and in building their capacity, or using their existing capacity.

1b. Technical assistance

- Help is needed in coalition building—"marketing what you do well and connecting with other agencies."

- 2. Availability of a continuum of services that ensure effective access and utilization.** Break-out group discussion under this topic centered around consumer education about availability and standards of service—the continuum of services that people should expect at each level of the disease. Several methods were suggested and included: surveys of agencies and consumers; brochures about everything the consumer needs to know about HIV and "is afraid to ask"; and videos for consumer viewing in waiting rooms. Each method needs to provide culturally specific information. The group agreed that quality of service should not be compromised as access is increased within the community. Topics to be addressed by these methods of consumer education include:

What can a patient expect from the listed HIV service?

- Costs to the consumer
- Contact person
- Frequency of services
- Written material
- Child care

- Transportation
- Expectations of the patient by the provider and vice versa
- Length of participation-Will I be penalized if I drop out of the program?
- Can I return?
- Statement of confidentiality
- Quality assurance
- Declaration of nondiscriminatory practices
- Need for qualified service providers
- Available language and culturally appropriate staff
- Good follow-up services
- Assured continuity of services

3. Identifying and institutionalizing community-based training and technical assistance models. Break-out group participants identified specific areas for technical assistance at the community-based level to increase effectiveness of African American organizations in accessing CARE Act resources. Participants identified both specific areas and approaches to be used for technical assistance.

3a. Key evaluation question

How best to address the technical assistance needs of African American organizations? Who can provide technical assistance most effectively?

3b. Technical assistance needs and possible sources of T/A.

NEED: Grant writing skills

Approach university centers and other non-profits and CBOs/compile list of agencies in area

Provide organizations a way to get help, e.g., funding for training and advocacy

Federal funds to hire grant writers

NEED: Acquiring/using statistics (numbers)

City planning, public health department

Documenting need/Conduct needs assessments of your clients

NEED: Reporting/report writing

Develop documents that show what you're doing

NEED: Staff

Use local people with experience in the community

NEED: Local certifications/licenses

Contact public agencies and facilitate with training

NEED: Acquiring 501(c)(3)

Help from other agencies, with expertise non-profit status (foundations)

NEED: Develop a strong board

Get them to “buy in” - empowerment; send them to workshops; select individuals with a variety of organizational skills

NEED: Collecting/managing data

Ask for assistance and develop cooperative relationships with other organizations

NEED: Conducting evaluation

Ask for help from funding sources, keep in contact

NEED: Developing community

Keep in contact with those you help; help those support other than your usual clients; ask them for political support

NEED: Acquiring knowledge

Network with people, agencies you know, resources ask people with HIV

NEED: Negotiating

Identify what you have to offer and what you local institutions need

NEED: Preparing a budget

Identify organizations and individuals with expertise

NEED: Becoming politically aware

Identify local politicians concerned about your interests

NEED: Coalition/partnership building

Identify mutual interests and work together

NEED: Accounting

Find agencies with similar needs and suggest cost sharing arrangements

NEED: Developing goals

Conduct community forums including objectives people at risk or with HIV, community agencies, informal and formal leaders

4. **Identifying resources of and for African Americans and developing a directory of services and skills.** In many communities African Americans with HIV are not aware of the resources available, their location and characteristics. There needs to be an understanding of how to effectively market the available resources to those in need in African American communities. Such a study might include the following issues:
 - 4a. Key evaluation research questions
 - Who are the African American service providers in the community?
 - What are African American-specific services like?
 - What skills are needed/specific to serving African Americans?
 - What/where are the African American-specific demonstration programs?
 - 4b. Likely indicators of services and skills
 - Technical assistance resources
 - Accounting/bookkeeping resources
 - Community organizations
 - Research resources
 - Evaluation resources
 - Program planning resources
5. **The development of organizations that move from “good works” to “good work.”** Break-out participants outlined suggestions and points relating to the development of more effective organizations. They stressed the need to distinguish and document effectiveness beyond well-intentioned activities. Often African American projects lack the ability to document to others their distinctive features and accomplishments, and they are under-appreciated. Community-based organizations must progress from “good works” (unevaluated performance) to “good work” (evaluated with objective measures) to be considered for funding.

Document:

- Outcomes: The distinctive strategies that are credible, relevant, and resonate with cultural values (“you need to show what you’ve done.”)
- Develop partnerships with networks of providers and umbrella organizations with resources (See Appendix 1).
- Assess costs and benefits associated with organizational development.

Benefits of Self-Assessment

- Ability to develop and maintain skills within the community.
- Ease of training.
- Can develop new and expedient (effective) communication ability.
- Maintaining contacts with grassroots.
- Can be funded.
- Cost effectiveness may increase.
- Increased resources.
- Enables quantitative and qualitative data collection for internal and external review.
- Reduce loss of autonomy.
- May need to share privileged information/Dissemination.
- Develop a local newsletter for informing other groups what is going on and for training.

II. Break-out Group #2

Participants: Jeffrey Henderson, Barbara Gomes-Beach, Keith Fabre and Nuri Ansari.

Break-out group #2 looked at the over-arching issue of decision-making arenas/planning council process (procedures to ensure funds go where they are needed, representation, representativeness, development of local agencies). Participants proposed evaluation studies that would address some of the key concerns that emerged from the first day’s African American work group discussions. The key concerns included:

- The fact that community priorities do not match funding allocations and funded organizations (sub-contractors). The board composition of funded organizations reflected non-existent or token African American involvement.

- Decision-making and planning council processes do not address the need for developing the infrastructure of CBOs to make them effective and recognized, including developing organizations within communities of African descent to:
 - respond to community needs;
 - write and implement grants effectively; and
 - manage, organize and implement programs of, by and for affected communities.
- Increasing the number and effectiveness of African American community members on review panels at HRSA, and at the local grantee level during the sub-contracting process.
- The need for community knowledge of CARE Act and grantee processes.

1. Key evaluation research questions

1a. Analyze the racial and ethnic composition of planning councils.

- Is the selection process equitable?
 - What are the eligibility criteria for planning councils and consortia representatives (are they inclusive of grass-roots and community leaders?)
 - Do they reflect the racial and ethnic demographics of the HIV epidemic (not just the demographics of reported AIDS cases) in the EMA?
 - Is there over-representation of some organizations and special interest groups?
 - Is the African American community, and are community-based organizations, aware of and involved in the planning council and consortia activities?
 - Are all segments of the African American population with HIV/AIDS represented on planning councils, even those not associated with organizations currently represented on planning councils?
 - Are there plans to increase the number and involvement of African Americans on planning councils and consortia?
 - Is there representation of grassroots African American CBOs on planning councils or consortia? Do the councils and consortia reflect the EMA's HIV epidemic demographics?

- Analysis of the proportion of ASOs' and CBOs' AIDS budgets designated to service African Americans with HIV.

- Do planning councils and consortia provide orientation and training for new planning council members?

1b. Analyze the planning council funding process.

- What is the process for allocation of Title I funds?
 - Which planning council committee determines funding priorities?
 - Is the process open to the community and are African American organizations encouraged to apply?
 - Is funding open to competitive bids?
 - Is there appropriate response time for RFPs?
 - Is technical assistance readily available and will it be delivered by an organization that is culturally competent?
- Do the funding allocations reflect the need?
 - Are the EMA's allocations proportionate to the number of African Americans with HIV?
 - Are services contracted out to African American organizations and then sub-contracted to other organizations? If so, to what kinds of organizations?
 - What percentage of CARE Act funds go to CBOs?
 - What percentage of CARE Act funds go to local health departments to perform services which could be provided by CBOs?
 - Is there a transition plan to move services for African Americans from public health departments to non-governmental African American community-based organizations?
 - Is there a system to evaluate the quality of services provided and are the results used to improve service delivery?
 - What is the fit between HIV priorities and the broader health and social services priorities in the African American community?

2. Likely variables and outcomes

Variables

- The level of awareness among CBOs and the African American community about the function of planning councils and consortia.
- Cultural sensitivity of the planning councils and consortia to African American issues.

- Planning council and consortia membership selection criteria used by EMAs.
- Extent to which African Americans are represented on planning councils and consortia.
- Accountability of planning councils and consortia to the community.
- Accountability of planning councils and consortia at HRSA and local government levels.

Outcomes

- Appropriate feedback from African American consumers.
- Client satisfaction.
- Underserved population characteristics and perceptions.
- Types and frequency of services.
- Culturally/linguistically appropriate services.
- Improved services to meet the medical, emotional, and spiritual needs of African Americans.
- Effective assistance with entitlements/accountability.

3. Suggested methods

- African American consumer needs assessments and service perception surveys should determine:
 - the consumer's perception of the services provided—Is there a “price of the ticket”? (degrading conditions within provider agencies that are accepted by clients who have no other options: “...‘the price of the ticket’ for getting treatment is ‘often going along with the system’ ...”);
 - the consumer's relationship to planning councils and consortia;
 - whether consumers are informed of, or involved in, planning council and consortia activities.
- An African American service organization's survey/interview should include:
 - questions about their relationship to the consumer, the local contractor, and HRSA.
- Observation of planning council and consortia meetings/activities should include:
 - questions about their relationship with HRSA, the CBOs and the consumer.
- Review planning council and consortia policies and procedures.

4. Characteristics of the study participants (subjects):

- The study should include a cross-section of the African American people with HIV disease and encompass cultural, political and socioeconomic diversity.

5. Recruitment issues

- Recruitment should be performed in ways that are culturally competent. Local African American people should be recruiters and use of financial incentives to encourage participation should be considered. Studies should be conducted in community-based locations which provide easy access to consumers. Consumers and CBOs should be allowed to provide input into the design of research studies and survey instruments.

6. Agencies interested in study findings

- HRSA, mid-sized and grassroots CBOs, ASOs, planning councils, as well as other agencies who receive CARE Act and other funding, would likely be interested in collaborating on the study.

III. Break-out Group #3:

Participants: Amanda Houston-Hamilton, Kay Brown, Sandra McDonald, Mireille Tribie, Don Wilson.

Compare two African American CBOs with two non-minority ASOs that have African American service components.

1. Key evaluation questions:

- What are the service models that accept African Americans with HIV on their terms and not as service categories that are predefined to fit a reporting requirement?
- What are the measures of cost-effective models that incorporate informal networks of providers versus treatment models without informal provider networks?
- What are the characteristics of outreach activities? Which factors are associated with successful outreach efforts in underserved African American communities?
- What are the characteristics of programs that effectively meet the information needs of African Americans and help get them into and keep them in care?
 - People are often told their HIV-positive status along with other information when receiving another service, such as: in-take

examinations for employment, Job Corps, and prison or blood product donation. Their lack of a basic understanding of HIV/AIDS or their sense of urgency when diagnosed may result in delays in seeking early or timely care.

- How do the testing services match the concept of what voluntary testing and counseling are all about?
- How do consumers learn about the range of HIV services they will need?

Treatment options

Legal

Vocational

Respite care

Family support systems

Child care

Secondary prevention

Tertiary prevention

Health and welfare benefits

Housing

Financial assistance

Recovery

Food

Transportation

- How are African American community-based options functioning/ utilized?
 - Cost effectiveness
 - Existing networks
 - Can they be mobilized?
 - Are they mobilized?
 - How can they be better supported?
 - Impact on the individual
 - Self esteem
 - Rehabilitation
 - Self care
 - Self advocacy
 - Community advocacy

- Acceptance of African American homosexuals
- How and what counseling is provided?
 - Reproductive issues
 - Family issues
 - Care-givers
 - Mental Health
 - Risk reduction/behavioral change
 - Opportunities for counseling
 - Recognizing HIV as one of many issues faced by clients
 - Recovery
 - Homelessness
 - Reaching people where “they’re at”—unconditional love
 - Listening to the client and writing the appropriate type of plan
 - Kids
- How and what treatment is provided?
 - Availability
 - Geographically
 - Waiting period (time span)
 - On demand
 - Alternatives
 - Credible
 - Culturally acceptable
 - Resources
 - Case management
 - Plan based on individual (holistic) medical needs
 - Provider sensitivity
 - Language appropriateness
 - Interaction quality
 - Training
 - Patient empowerment
 - Community involvement including people with HIV disease

- How and what practical support is provided?
 - Increased recognition of the informal services delivered in the community:
 - Church-based counseling and other services
 - Person power
 - Need for collaboration
 - Need to redefine practical support and move away from the model based on the gay white male experience toward a model that recognizes the family as client.
- How and what training is provided (to, for and by African Americans)
 - Providers
 - Addiction/recovery
 - Sexuality
 - Hands-on apprenticeships
 - Care-givers/family
 - Universal precautions
 - Respite
 - Options
 - Legal matters (wills, etc.)
 - Co-dependency
 - Nutrition
 - Sexuality
 - Death/dying
 - Individual
 - Nutrition
 - Communication
 - Options
 - Personal advocacy/leadership
 - Relationships

2. Likely variables and outcomes:

- Underserved client characteristics (demographics)
- Client satisfaction
- Types of services and frequency of use

- Communication style
- When accessed or used in the disease process?
- How found?/referral process
- Why do some clients return for service and others do not?
Agency responsiveness as measured by the ability to serve the uninsured, not just those who have an ability to pay

3. Characteristics of people to be studied:

Individuals from communities of African descent, including diverse ethnic/cultural backgrounds:

- Caribbean
 - French/Creole speaking
 - Dutch speaking
 - English speaking
 - Spanish speaking
 - Ethnic/regional African American identity
 - Socio-economic demographics, including educational, high risk behavior, regional and urban/rural characteristics
- 4. Agencies interested in collaborating on each study:**
- It was recommended that one of each of three types of organizations be compared in three major urban centers: (1) a major ASO, (2) an African American CBO, and (3) a community health center. Other types might be identified for comparison purposes.

5. Agencies interested in each study's findings:

All need to know: Federal, State and local.

Appendices

| | |
|--|-----|
| Illustration: Information Systems that Work | A-1 |
| Illustration: Development of Organizations that Move From “Good Works” to “Good Work” | A-2 |
| Participant Listing | A-3 |
| Agenda | A-4 |

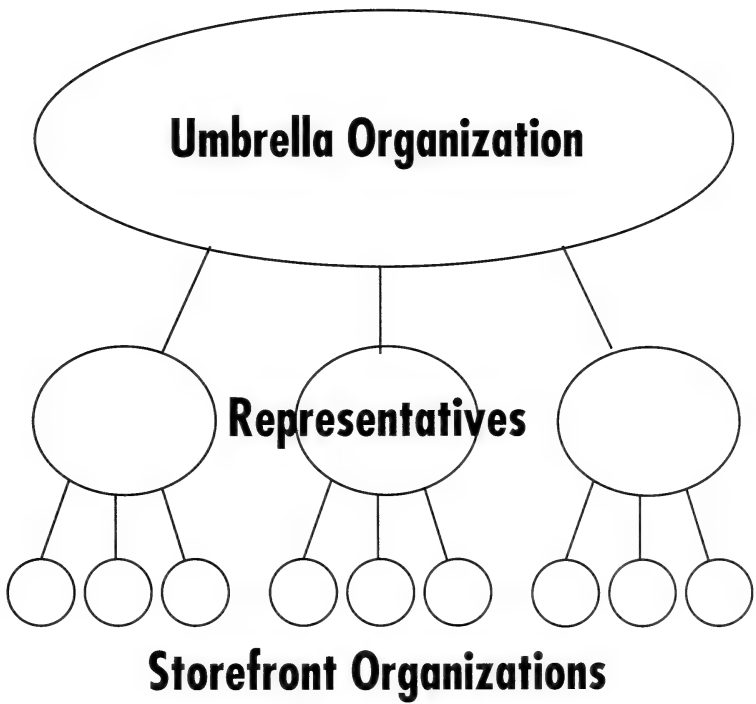
Appendix A-1

Information Systems That Work Information Exchange



Appendix A-2

**Development of Organizations
That Move From
"Good Works" to "Good Work"**



Appendix A-3

Participant Listing

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Appendix A-4

AGENDA

AFRICAN AMERICAN WORK GROUP ON BARRIERS TO RYAN WHITE HIV CARE

Residence Inn, Bethesda, Maryland

February 22-23, 1993

February 22

- | | |
|---------------|---|
| 8:30 - 8:45 | Introductions—Moses Pounds (<i>HRSA and BHRD Staff Participants</i>) |
| 8:45 - 9:15 | Discussion of objectives and logistics (<i>Moses Pounds</i>) |
| 9:15 - 9:45 | Discussion of barriers to access issues (Led by <i>Moses Pounds</i> and <i>Gary Cook</i>) |
| 9:45 - 10:00 | Break |
| 10:00 - 12:30 | PRESENTATIONS OF PERCEPTIONS OF SERVICES |
| 10:00 - 11:00 | Baltimore Ethnographic Project (<i>Tony Whitehead</i>) |
| 11:00 - 12:00 | Oakland Ethnographic Project (<i>Amanda Houston-Hamilton</i>) |
| 12:00 - 1:00 | Further discussion of barriers to care topics for work groups development and technical assistance |
| 1:00 - 2:00 | Lunch |
| 2:00 - 3:30 | Identification of barriers to care issues for break-out groups and assignment of participants to break-out groups |
| 3:30 - 5:00 | Initial meeting of break-out groups to design evaluation studies |

February 23

- | | |
|-------------|--|
| 8:30 - 2:30 | Break-out group meetings (<i>participants and staff</i>) |
| 3:30 - 5:00 | Report of break-out groups' draft evaluation studies (<i>Federal and non-federal HIV/AIDS agencies will attend</i>) |





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